



## King's Research Portal

DOI:

[10.2215/CJN.11861115](https://doi.org/10.2215/CJN.11861115)

*Document Version*

Peer reviewed version

[Link to publication record in King's Research Portal](#)

*Citation for published version (APA):*

Morton, R. L., Webster, A. C., McGeechan, K., Howard, K., Murtagh, F. E. M., Gray, N. A., Kerr, P. G., Germain, M. J., & Snelling, P. (2016). Conservative Management and End of Life Care in an Australian Cohort with ESRD. *Clinical journal of the American Society of Nephrology : CJASN*, 11(12), 2195.  
<https://doi.org/10.2215/CJN.11861115>

### **Citing this paper**

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

### **General rights**

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

### **Take down policy**

If you believe that this document breaches copyright please contact [librarypure@kcl.ac.uk](mailto:librarypure@kcl.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.

1 **Title:** Conservative management and end-of-life care: Three-year follow-up of an Australian cohort with end-stage  
2 kidney disease.  
3

4 **Authors and affiliations:**  
5 Rachael L Morton,<sup>1</sup> PhD  
6 Angela C Webster,<sup>2</sup> PhD  
7 Kevin McGeechan,<sup>2</sup> PhD  
8 Kirsten Howard,<sup>2</sup> PhD  
9 Fliss EM Murtagh,<sup>3</sup> PhD  
10 Nicholas A Gray,<sup>4</sup> MBBS  
11 Peter G Kerr,<sup>5</sup> MBBS, PhD  
12 Michael J Germain,<sup>6</sup> MD  
13 Paul Snelling,<sup>7</sup> MBChB  
14

15 **Institutions:** <sup>1</sup>NHMRC Clinical Trials Centre, The University of Sydney, Camperdown, Australia, 2050  
16 <sup>2</sup>School of Public Health, The University of Sydney, Camperdown, Australia, 2050  
17 <sup>3</sup>Cicely Saunders Institute, King's College London, Denmark Hill, United Kingdom  
18 <sup>4</sup>The University of Queensland, Sunshine Coast Clinical School, Nambour General Hospital, Nambour, Australia, 4560  
19 <sup>5</sup>Monash Medical Centre, Clayton, Australia, 3168  
20 <sup>6</sup>Baystate Medical Center, Springfield, United States, 01107  
21 <sup>7</sup>Royal Prince Alfred Hospital, Camperdown, Australia 2050  
22

23 **Corresponding author:** Rachael L Morton, Level 6, NHMRC Clinical Trials Centre, Medical Foundation Building, The  
24 University of Sydney, Camperdown, NSW, 2050.  
25 Tel: +61 2 9562 5013; Fax: +61 2 9565 1863; Email: rachael.morton@ctc.usyd.edu.au  
26

27 **Running title:** End-of-life care in Australia  
28 **Key words:** renal dialysis; palliative medicine; advance directives; hospices; kidney failure, chronic  
29

30 Word limit: 3152  
31 Abstract word limit: 299  
32 References: 30  
33 Tables: 5  
34 Figures: 2  
35 Webtables: 4  
36 Webfigures: 1  
37 **Funding:** Kidney Health Australia – Project Grant #PG2012**Study registration:** Clinicaltrials.gov ID #NCT01768624



**Abstract:**

**Background and Objectives:** We aimed to determine the proportion of patients who switched to dialysis after confirmed plans for conservative care; and compare survival and end-of-life care among patients choosing conservative care, with those initiating renal replacement therapy (RRT).

**Design, setting, participants, and measurements:** Cohort study of 721 incident dialysis, transplant and conservatively managed patients from 66 Australian renal units entered into the Patient Information about Options for Treatment (PINOT) study, 1<sup>st</sup> July – 30<sup>th</sup> September 2009, followed for 3 years. A two-sided binomial test assessed the proportion of patients that switched from conservative care to RRT. Cox regression, stratified by center, adjusted for patient and treatment characteristics estimated factors associated with 3-year survival.

**Results:** 102 of 721 patients planned for conservative care, median age 80 years. Of these 8% (95%CI 3-13%), switched to dialysis, predominantly for symptom management. Of 94 patients remaining on a conservative pathway, 18% were alive at 3 years. Of the total 721 patients, 247 (34%) died by study end. In multivariable analysis factors associated with all-cause mortality included older age (HR 1.55, 95%CI 1.36-1.77); baseline serum albumin <3.0g/dL vs. 3.7-5.4g/dL (HR 4.31, 95%CI 2.72-6.81), and management with conservative care compared with RRT (HR 2.18, 95%CI 1.39-3.40). Of 247 deaths, patients managed with RRT were less likely to receive specialist palliative care (26% vs 57%,  $p<0.001$ ); more likely to die in hospital (66% vs 42%,  $p<0.001$ ) than home or hospice; and more likely to receive palliative care only within the last week of life (42% vs 15%,  $p<0.001$ ) than those managed conservatively.

**Conclusions:** Survival after 3 years of conservative management is common with relatively few patients switching to dialysis. Specialist palliative care services are utilized more frequently and at an earlier time point for conservatively managed patients, a practice associated with better symptom management and quality-of-life.

## Introduction:

In the UK and Australia, up to 20% of patients with stage 5 chronic kidney disease (CKD), referred to a nephrologist and informed of their treatment options, choose conservative care.(1-3) Comprehensive conservative care is defined as planned holistic patient-centered care for people with stage 5 CKD that includes interventions to delay progression of kidney disease and minimize risk of adverse events; shared decision making; active symptom management; detailed communication including advance care planning; psychological, social and family support; cultural and spiritual care; but does not include renal replacement therapy (RRT).(4, 5) The focus of conservative care incorporating palliative care principles, is to prioritize comfort and quality of life aligned with patients' goals of care, rather than a conventional disease-orientated focus on renal replacement therapy (particularly dialysis) as rehabilitative treatment.(6) It has been reported that patients initially choose conservative care, but may change their minds and commence dialysis once their kidney function deteriorates and they feel unwell.(7-9) However, it is unclear what proportion of patients switch to dialysis after an initial plan for conservative care.

Palliative care service provision and access to hospice care is variable in Australia and other countries for people with non-malignant conditions. Several studies (10-12) report limited access to specialist palliative care for patients with end-stage kidney disease (ESKD). Some reasons for this include a workforce shortage of palliative care clinicians, lack of recognition of the need for palliative care symptom management for patients managed with dialysis, poor education and training in palliative care for nephrologists, and nephrologists feeling reluctant to discuss that a patient is near the end of their life.(13-15) There is also a recognition that the nephrologists' role in provision of palliative care is evolving, however questions remain about optimal models of care and the best time for referral to palliative care services. There are new initiatives looking at different models of renal supportive care that include palliative care. For example, the Agency for Clinical Innovation in Australia has funded a pilot program of specialist nurses to provide renal supportive care. (<http://www.aci.health.nsw.gov.au/about-aci/e-news/newsletter/february-2015/sections/renal2>)

The Patient INformation about Options for Treatment (PINOT) study was a prospective national cohort of incident dialysis, transplant and conservatively managed patients enrolled between July and September 2009 followed for 3

years.(3, 16) PINOT was designed to investigate the information about treatment options incident patients with ESKD received prior to starting treatment; and then to follow the cohort to assess renal and palliative care service provision and mortality outcomes over a 3-year period. This cohort from Australian renal units provides a nationally representative sample in which to assess changes in type of treatment and patterns of end-of-life care. We aimed to determine the proportion of patients who commenced dialysis, or a time-limited trial of dialysis within 3 years after confirmed plans for conservative care, and compare survival and end-of-life care among patients choosing conservative care, to those initiating RRT. In addition, we were interested in documenting the prevalence of advance care directives; the use of the surprise question in prognostication(17, 18); and the location of participants' place of death.

## **Materials and Methods:**

### *Setting*

The PINOT study was conducted among 66 Australian renal units including each state and territory. The PINOT cohort represented 95% of all patients commencing RRT for the 3-month intake period and included all known incident patients with an eGFR of less than 15ml/min/1.73m<sup>2</sup>, and a confirmed plan for conservative care. Further details are described in the Technical appendix.

### *Methods of follow-up for the PINOT cohort*

In 2012, a detailed questionnaire was sent to each participating renal unit to confirm the patient's baseline demographics; document dialysis and/ or conservative care activity between 1<sup>st</sup> July 2009 and 30<sup>th</sup> September 2012; and survival status as at 30<sup>th</sup> September 2012.(See Appendix) The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) was used to confirm changes in RRT, and both this and the Ryerson Death Index were used to confirm notification of deaths. The study was approved by relevant Health Research Ethics Committees, with a waiver for informed consent and was prospectively registered as an observational study on Clinicaltrials.gov#NCT01768624.

### *Outcomes*

The primary outcome was the proportion of conservatively managed patients who switched to dialysis or commenced a time-limited trial of dialysis during follow-up (July 2009-30<sup>th</sup> September 2012). We hypothesized that nationally, this proportion would be less than 15%, based on available small or single-center studies from the UK and Australia that reported a switch to dialysis of between 2-16%.(7-9) The secondary outcomes of the follow-up study included 3-year survival among patients who initially commenced conservative care at study baseline compared with patients who commenced RRT at baseline. Survival was verified through hospital and primary care records, ANZDATA records and where unknown, to the Ryerson Death Index, an organization that reviews death notices and obituaries in Australian newspapers.(19) To determine the prevalence of a documented advance directive, (a legal document intended to record or instruct a patient's preference for future health and personal care should decision-making capacity become impaired)(20); patient's medical records and renal care plans were searched. The presence of an advance directive included either a copy of the advance directive in the patient's notes, or a documented acknowledgement in the patients' notes that the individual did indeed have an advance directive that stated their wishes. Similarly, medical records were searched for the documented use of the "surprise" question for prognostication (17) that is, "Would I be surprised if this patient died in the next year?" The provision and timing of specialist palliative care services that were utilized for patients who died during the follow-up period, and the location of patients' place of death (i.e. hospital, hospice, home), was sourced through hospital and hospice records, doctors' letters and primary care records. Regular palliative care medical services were defined as hospital or community-appointed palliative care specialist physicians, rather than a joint nephrology/palliative care service that included a nephrologist.

#### *Statistical methods*

Differences between groups were assessed using Pearson's chi-square or Fisher's exact test for categorical variables, and two sample t-test for continuous variables. A two-sided binomial test was performed to assess the proportion of patients that switched from conservative care to renal replacement therapy from a hypothesized value of <15%. Cox proportional hazards models were used to estimate factors associated with 3-year mortality. The hazard ratios and their 95%CI for each factor are presented both unadjusted and stratified by center and adjusted for age, sex, home language, marital status, socio-economic status, remoteness, health insurance, late referral to a nephrologist, serum

albumin and haemoglobin. Missing data for baseline biochemistry and deaths was addressed by using complete case analysis. The number of participants who were lost to follow-up and the reasons for loss to follow-up were reported by initial treatment modality. All analyses were performed using STATA version 13.1. We followed the STROBE statement for reporting observational studies.(21)

## **Results:**

### *Participants*

Seven hundred and twenty-one participants, mean age 63 years (SD 17.5), were enrolled in the study in 2009.(Figure 1) Of these, 5 (1%) died before starting planned treatment. At the time of enrolment, 102 (14%) planned for conservative care, 589 (82%) commenced dialysis and 25 (3%) received a pre-emptive kidney transplant. For the 3-year follow-up study, 64 of 66 renal units agreed to participate; the 2 that declined did so due to inadequate staffing to complete the follow-up questionnaires. After 3 years of follow-up, 247 (34%) patients were deceased; 416 (58%) alive and 58 (8%) lost to follow-up. All remaining patients (n=663) were included in the analyses for survival and end-of-life care outcomes.(Figure 1)

Patients who elected for conservative care at baseline were on average older (median age 80 vs 64 years), and more likely to have lost a partner (40% vs 16%) than those who commenced RRT.(Table 1) There was no significant difference between the groups for area-based socio-economic status ( $p=0.74$ ), geographic remoteness ( $p=0.17$ ), home language ( $p=0.80$ ), time known to a nephrologist ( $p=0.10$ ), baseline serum albumin ( $p=0.68$ ) or hemoglobin ( $p=0.99$ ).(Table 1)

### *Main results*

Of the 102 patients who planned for conservative care, 8 (8%) switched to dialysis within the 3 year follow up, (95%CI 3-13%,  $p$ -value for difference from hypothesized value of 15%,  $=0.04$ ).(Table 2) The primary reason for commencement of dialysis was symptom management, primarily uremic symptoms and/or fluid overload. The outcomes of these 8 patients are described in Table 3. Three of the 8 patients were started on a time-limited trial of dialysis that continued for 3 days, 118 days, and in one case was ongoing at study end after 638 days. .(Table 2)



Dialysis access was created for 10 conservatively managed patients, and this was unused in 2 patients.(Table 2) Of 102 patients who initially commenced conservative care, 23% (95%CI 15-31%) were alive at 3 years, including those who switched to dialysis. Of those who did not commence dialysis (n=94), 17 (18%) were still alive at 3 years. The survival status of 10 conservatively managed patients was unable to be ascertained, however there was no evidence from the ANZDATA Registry that they commenced dialysis.

Among the entire cohort of 721 patients, there were 247 deaths. Higher 3-year mortality was associated with older age (HR 1.55, 95%CI 1.36-1.77); serum albumin at baseline <3.0g/dL vs. 3.7-5.4g/dL (HR 4.31, 95%CI 2.72-6.81), and management with conservative care compared with RRT (HR 2.18, 95%CI 1.39-3.40). (Webfigure 1, Webtable 2) Of the 247 deaths, 77 were within 6 months (26 conservative, 51 RRT), 121 were within one year (41 conservative, 80 RRT) and 180 were within two years (59 conservative, 121 RRT). 46 of 721 patients had a documented advance directive; with conservatively managed patients more likely to have one than RRT patients (21% vs 4%, <0.001).(Table 4) The main themes related to the presence or absence of an advance directive are tabulated in Webtable 3. The “surprise” question was infrequently identified in the patients’ medical records, however was more likely to be documented among conservative care patients than RRT patients (difference 6%, [95%CI for difference 2%-13%]). (Table 4)

Of 247 deaths, patients on RRT were more likely to die in hospital and less likely to die in hospice than patients managed conservatively.(Table 5) Eighty-six of 247 patients received specialist palliative care. A greater proportion of conservative care patients received specialist palliative care than did RRT patients (57% vs 26%, <0.001).(Table 5) Patients managed with RRT were more likely to receive palliative care only during the last week of life (42% vs 15%, p<0.001) than patients managed conservatively.(Table 5, Figure 2) Of the five patients who switched from conservative care to RRT and died within the study period, two were referred for palliative care. Of those with advance directives (n=21), 9(43%) were treated with inpatient acute palliative care; and 12(57%) were treated with outpatient care. Two patients (10%) were managed within a joint nephrology palliative care service and 17 (81%) with existing regular palliative care services. Of those who died in hospice (n=16), equal numbers (8 each) were treated with inpatient acute palliative care, for those admitted to hospital and outpatient care, for those at home. Three patients (19%) were managed in a joint nephrology palliative care service and 12 (75%) managed in

existing regular palliative care. The major themes regarding advance directives and the location of patient deaths are outlined in Webtables 3 &4.

## **Discussion**

Our national follow-up study suggests less than 10% of patients who initially choose conservative care switch to dialysis within 3 years. One in five patients with ESKD who commenced conservative care (mean age 80 years) were still alive at 3 years, and this figure may be larger as there were no death records identified for the 10 participants whose survival status was unknown. Among the whole cohort, factors associated with all-cause mortality included older age, low serum albumin at study baseline and management with conservative care compared to RRT. Of patients who died during the 3 year follow-up period, those managed with RRT were less likely to receive specialist palliative care and more likely to die in hospital than home or hospice. Patients managed with RRT were more likely to receive palliative care only within the last week of life than patients managed conservatively.

Referral to hospice and deaths in hospice is low for patients with ESKD globally, and very low for Australian patients with ESKD compared to the US.(10) However, the rate identified in our study is not dissimilar to population-based reports of hospice deaths for Australian patients with cancer. For example, in 2003 in New South Wales, (Australia's most populous state) only 7.5% of cancer deaths were in a dedicated palliative care institution (i.e. hospice), compared to 55.5% deaths in public hospitals, 10% in private hospitals, 10% nursing home and 17% at home.(22) This is likely a result of a low number of hospice facilities overall; the creation of palliative care beds within public hospitals and restrictions of hospice services to particular local area health districts.

## **Limitations**

Despite our best efforts to follow up all patients in the PINOT cohort, 58 (8%) were lost to follow-up and their survival status could not be ascertained. Forty-five of these patients (87%) came from the 2 renal units who were unable to participate in the follow-up study and were initially managed with dialysis; 10 of 102 conservatively managed participants were lost to follow-up. A review of ANZDATA records did not find evidence that these patients

commenced dialysis within the follow-up period, and were therefore most likely managed in the community. In addition, comorbid conditions were not systematically recorded for the PINOT cohort so we were unable to include this data in the analyses in a meaningful way.

Further, our study relied on the presence of documented medical records, which may not be complete, and therefore any estimates of palliative care service provision or presence of documented advance directives may have been underestimated. In the majority of Australian renal units an advance directive is usually “highlighted” in an electronic record, or color-coded in patients’ medical notes to facilitate rapid identification, and hence the chance of missing a documented record was likely very low.

### *Interpretation*

Few patients switched to dialysis after a confirmed plan for conservative care, consistent with other studies.(7, 9) (8) The low rate of crossover from conservative management to RRT may indicate more anticipatory discussions among those with structured and early access to palliative care. Our results suggest that structured access to palliative care may avoid the emergent dialysis in the Emergency Department or ICU for those who have decided to not pursue RRT but end up starting in a catastrophic situation. Of the 8 patients in our study who did switch to dialysis, 5 died within a mean of 218 days (range 3 to 536 days) and 3 were still alive after 3 years follow-up. These numbers are too small for any meaningful interpretation, and our data did not include measures of quality-adjusted survival, that might inform assessment of the value of any survival benefit. We are unable to know whether the survival time would have been different for these 3 patients had they remained on conservative care. Until we better understand what makes some patients satisfactorily manage dialysis, nephrologists are limited in how they can advise their patients.

Patients on RRT are significantly more likely to die in hospital and less likely to die in hospice. This finding is echoed in two single-center studies in the UK.(23) (2) The proportion of dialysis patients who died in hospital in our study (66%) is higher than the Australian average for hospital deaths of 54%, (24) and may reflect deaths due to withdrawal of dialysis. While systematic reviews commonly report the general public has a preference for dying at home,(25, 26) it is possible that dialysis withdrawal may be preferred on a renal ward where the patients and their

family members are well known to the renal staff. Further research in this area is needed, as in many places Australian nephrologists cannot access palliative care for people on dialysis until treatment is withdrawn. Therefore while our finding is not surprising, it reflects the lack of access to palliative care services from a health system that regards RRT as on-going treatment and not representing a palliative care context. It is important that people with ESKD are recognized as needing specialist palliative care services, regardless of whether they are on dialysis or managed conservatively.

The low rate and late involvement of palliative care, and low rate of advance directives in the RRT group may signal nephrologists and/or family members not broaching the subject of end-of-life care among a population with high mortality rates. Similarly the low prevalence of documentation of the surprise question, validated in dialysis patients,(17, 18) may mean the question is not used, or if used, not documented. This might also suggest that prognosis is communicated to patients infrequently. A recent survey found 97% of Australian and New Zealand nephrology fellows over the last 10 years reported conservative care being a very important skill, but only 43% reported being well trained in it.(27) This represents an area for clinical improvement and education programs for nephrology trainees have begun to address this need. Quality metrics for palliative care suggest palliative care involvement within days of death is considered a marker of poor care in other specialties.(28) Further research is needed to determine the outcomes for those patients who have advanced kidney disease and receive palliative care.

Specialist palliative care services were used more frequently in end-of-life care among people managed conservatively, however this was still only for 57%. Similarly, the prevalence of advance directives was relatively low among those with planned conservative care. The prevalence of advance directives among adults with end-stage kidney disease is not well understood. One small study of 19 dialysis patients in the US reported 32% had advance directives,(29) and another single-center study of 182 dialysis patients reported 41% had stated their advance directives either verbally or in writing.(30)

### *Generalizability*

There is very little national data available for conservatively managed patients, as long-term follow-up often occurs in the community and is not routinely recorded in a registry. Our study provides 3-year follow-up data for a

representative cohort of national incident patients with ESKD, including all age groups, ethnicities, socio-economic status, and from metropolitan, rural and remote geographical locations. Our outcomes are likely to be similar to other countries that offer dialysis, transplantation, and comprehensive conservative care. The end-of-life care results however may differ to other countries with alternate financing and structures of palliative care services and/or streamlined access to hospice for people with ESKD. Although the Australian population with ESKD is culturally and linguistically diverse, results may differ among populations with different cultural or religious beliefs about death and dying.

### *Conclusion*

Our study suggests survival after 3 years of conservative care is common with relatively few patients switching to dialysis. Specialist palliative care services are utilized more frequently and at an earlier time point for conservatively managed patients, a practice that is associated with better symptom management and quality of life.

*Funding:* The PINOT follow-up study was funded by Kidney Health Australia and the Australian National Health and Medical Research Council (NHMRC) capacity building grant in health economics #571372. Rachael Morton is funded through the NHMRC Sidney Sax ECR Fellowship #1054216.

*Disclosures:* None

## References:

1. Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood RN, Farrington K: Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrol Dial Transplant*, 26: 1608-1614, 2011
2. Smith C, Da Silva-Gane M, Chandna S, Warwicker P, Greenwood R, Farrington K: Choosing not to dialyse: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pract*, 95: c40-46, 2003
3. Morton RL, Howard K, Webster AC, Snelling P: Patient INformation about Options for Treatment (PINOT): a prospective national study of information given to incident CKD Stage 5 patients. *Nephrol Dial Transplant*, 26: 1266-1274, 2011
4. Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F, Murtagh FE, Naicker S, Germain MJ, O'Donoghue DJ, Morton RL, Obrador GT: Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int*, 88: 447-459, 2015
5. Murtagh FEM BA, Moranne O, Morton RL, Naicker S,: Comprehensive Conservative Care in End-Stage Kidney Disease. *Clin J Am Soc Nephrol*, 2016
6. Grubbs V, Moss AH, Cohen LM, Fischer MJ, Germain MJ, Jassal SV, Perl J, Weiner DE, Mehrotra R: A palliative approach to dialysis care: a patient-centered transition to the end of life. *Clin J Am Soc Nephrol*, 9: 2203-2209, 2014
7. Roderick P, Rayner H, Tonkin-Crine S, Okamoto I, Eyles C, Leydon G, Santer M, Klein J, Yao GL, Murtagh F, Farrington K, Caskey F, Tomson C, Loud F, Murphy E, Elias R, Greenwood R, O'Donoghue D: Health Services and Delivery Research. In: *A national study of practice patterns in UK renal units in the use of dialysis and conservative kidney management to treat people aged 75 years and over with chronic kidney failure*. Southampton (UK), NIHR Journals Library, 2015,
8. Tonkin-Crine S, Okamoto I, Leydon GM, Murtagh FE, Farrington K, Caskey F, Rayner H, Roderick P: Understanding by older patients of dialysis and conservative management for chronic kidney failure. *Am J Kidney Dis*, 65: 443-450, 2015
9. Brown MA, Collett GK, Josland EA, Foote C, Li Q, Brennan FP: CKD in elderly patients managed without dialysis: survival, symptoms, and quality of life. *Clin J Am Soc Nephrol*, 10: 260-268, 2015
10. Murray AM, Arko C, Chen SC, Gilbertson DT, AH M: Use of hospice in the United States dialysis population. *Clin J Am Soc Nephrol*, 1: 1248-1255, 2006

11. Kurella Tamura M, Cohen LM: Should there be an expanded role for palliative care in end-stage renal disease? *Curr Opin Nephrol Hypertens*, 19: 556-560, 2010
12. Pivodic L, Pardon K, Van den Block L, Van Casteren V, Miccinesi G, Donker GA, Alonso TV, Alonso JL, Aprile PL, Onwuteaka-Philipsen BD, Deliens L: Palliative care service use in four European countries: a cross-national retrospective study via representative networks of general practitioners. *PLoS One*, 8: e84440, 2013
13. Fassett RG, Robertson IK, Mace R, Youl L, Challenor S, Bull R: Palliative care in end-stage kidney disease. *Nephrology*, 16: 4-12, 2011
14. Brown MA, Masterson R: Renal palliative care in Australia: time to engage. *Nephrology*, 16: 2-3, 2011
15. Davison SN, Jhangri GS, Holley JL, Moss AH: Nephrologists' reported preparedness for end-of-life decision-making. *Clin J Am Soc Nephrol*, 1: 1256-1262, 2006
16. Morton RL, Howard K, Webster AC, Snelling P: Patient information about options for treatment: Methods of a national audit of information provision in chronic kidney disease. *Nephrology*, 15: 649-652, 2010
17. Moss AH, Ganjoo J, Sharma S, Gansor J, Senft S, Weaner B, Dalton C, MacKay K, Pellegrino B, Anantharaman P, Schmidt R: Utility of the "Surprise" Question to Identify Dialysis Patients with High Mortality. *Clin J Am Soc Nephrol*, 3: 1379-1384, 2008
18. Cohen LM, Ruthazer R, Moss AH, Germain MJ: Predicting Six-Month Mortality for Patients Who Are on Maintenance Hemodialysis. *Clin J Am Soc Nephrol*, 5: 72-79, 2010
19. Ryerson Index Inc: The Ryerson Index to death notices and obituaries in Australian newspapers. New South Wales, Australia, 2015
20. Royal Australian College of General Practitioners (RACGP): Advance Care Planning. Practice guides and tools. Melbourne, Australia, Royal Australian College of General Practitioners 2014
21. von Elm E, Altman DG, Egger M, Pocock SJ, Gotsche PC, Vandenbroucke JP: Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *BMJ*, 335: 806-808, 2007
22. Tabor B TE, Glare P, Roder D,: Place of Death of People with Cancer in NSW. A Population Based Study. In: NEW SOUTH WALES DEPARTMENT OF HEALTH (Ed.) Sydney, Cancer Institute NSW, 2007
23. Carson RC, Juszczak M, Davenport A, Burns A: Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease? *Clin J Am Soc Nephrol*, 4: 1611-1619, 2009

24. Broad JB, Gott M, Kim H, Boyd M, Chen H, Connolly MJ: Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *Int J Public Health*, 58: 257-267, 2013
25. Bell CL, Somogyi-Zalud E, Masaki KH: Methodological review: measured and reported congruence between preferred and actual place of death. *Palliat Med*, 23: 482-490, 2009
26. Higginson IJ, Sen-Gupta GJ: Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med*, 3: 287-300, 2000
27. Beaton TJ, Krishnasamy R, Toussaint ND, Phoon RK, Gray NA: Nephrology Training in Australia and New Zealand: A Survey of Outcomes and Adequacy. *Nephrology*, doi: 10.1111/nep.12720, 2016
28. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S: Identifying potential indicators of the quality of end-of-life cancer care from administrative data. *J Clin Oncol*, 21: 1133-1138, 2003
29. Weisbord SD, Carmody SS, Bruns FJ, Rotondi AJ, Cohen LM, Zeidel ML, Arnold RM: Symptom burden, quality of life, advance care planning and the potential value of palliative care in severely ill haemodialysis patients. *Nephrol Dial Transplant*, 18: 1345-1352, 2003
30. Swartz RD, Perry E: Advance directives are associated with "good deaths" in chronic dialysis patients. *J Am Soc Nephrol*, 3: 1623-1630, 1993



Table 1. Patient characteristics categorized by baseline treatment modality

Characteristic at study baseline	Conservative care n=102 (14%)		Renal replacement therapy n=619 (86%)		P value for difference between groups <sup>a</sup>
Age (years)					<0.001
Mean (SD)	79	(9)	61	(17)	
Median (IQR)	80	(75-85)	64	(50-74)	
Sex					0.09
Males	52	51%	371	60%	
Females	50	49%	248	40%	
Marital status					<0.001
Married / de facto	43	44%	308	52%	
Single	5	5%	82	14%	
Separated / divorced/ widowed	41	40%	100	16%	
Unrecorded	13	11%	129	18%	
Area deprivation index					0.74
High SES (deciles 8-10)	20	20%	158	26%	
Mid SES (deciles 4-7)	38	37%	267	43%	
Low SES (deciles 1-3)	28	27%	174	28%	
Unrecorded	16	16%	20	3%	
ARIA – remoteness index					0.17
Major city	55	54%	348	56%	
Inner regional	24	23%	145	24%	
Outer regional	5	5%	69	11%	
Remote or very remote	2	2%	37	6%	
Unrecorded	16	16%	20	3%	
Type of health insurance					0.19
Public only	57	56%	418	68%	
Private	13	13%	136	22%	
Veterans' Affairs	5	5%	19	3%	
Unrecorded	27	26%	46	7%	
Language spoken at home					0.80
English	82	80%	491	79%	
Other <sup>b</sup>	20	20%	128	21%	
Interpreter required					0.69
Yes	11	11%	59	10%	
Time known to a nephrologist					0.10
> 2 years	54	52%	252	41%	
1-2 years	18	18%	114	18%	
3-12 months	15	15%	111	18%	
< 3 months	15	15%	142	23%	
eGFR ml/min/1.73m <sup>2</sup>	<15	-	On dialysis	-	
Serum albumin g/dL					0.68
n, mean (SD)	82, 3.25	(0.57)	513, 3.28	(0.63)	
Hemoglobin g/dL					0.99
n, mean (SD)	82, 10.68	(1.57)	513, 10.68	(1.56)	

Percentages presented are row percentages

SD = standard deviation, IQR = inter-quartile range, SES = socio-economic status, ARIA = Accessibility / Remoteness Index of Australia

<sup>a</sup>Pearson's chi-square test for difference between groups, excluding 'unrecorded' group

<sup>b</sup>Other language includes predominantly Greek, Italian, Arabic, Chinese, Vietnamese and Indigenous languages

Table 2. Dialysis access creation and initiation during the 3-year follow-up period among 102 patients who chose conservative care at study baseline

Characteristic	n	%	95%CI
First dialysis access created <sup>b</sup>			
Fistula / Vascular catheter	7	7%	(2%-12%)
Peritoneal dialysis catheter	3	3%	(1%-8%)
No access	85	83%	(76%-90%)
Unknown	7	7%	(2%-12%)
Dialysis commenced			
Yes	8	8%	(3%-13%)
No	87	85%	(77%-91%)
Unrecorded	7	7%	(2%-12%)
Primary reason for commencement of dialysis			
Symptom management	4	50%	(22%-78%)
Time-limited trial of dialysis	3	38%	(14%-69%)
Emergency / Intensive care unit admission	1	12%	(2%-47%)

<sup>b</sup>Dialysis access was created for 10 of 102 patients, 8 of these patients commenced dialysis.

Table 3. Survey details for the 8 conservative care patients who commenced dialysis within the 3-year follow-up period

Treatment summary	Survival status at 3 years	Survival duration following initiation of dialysis (days)
47 year old female, initially chose conservative care, started APD then HD, continues on HD	Alive	1067
71 year old male, initially chose conservative care, however after several hospital admissions family insisted on dialysis, changed to center HD	Alive	797
60 year old female, bipolar disorder, refused all treatment initially, but did not want discussions about end of life care, had PD catheter inserted, but later commenced center HD (Time limited trial)	Alive	638
80 year old female, physician started APD, patient withdrew from therapy (Time limited trial)	Deceased	3
75 year old female, started acute HD in ICU for symptom management	Deceased	7
71 year old male, commenced HD when he became unwell, cognitively impaired but adamant about wanting dialysis, (Time limited trial)	Deceased	118
85 year old male, admitted from ICU, commenced center HD for symptom management, commenced dialysis	Deceased	426
74 year old female, commenced HD for symptom management, MI on dialysis	Deceased	536

APD = automated peritoneal dialysis, HD = hemodialysis, ICU = intensive Care Unit, MI = myocardial infarction

Table 4. Use of Advance Care Directives and the “Surprise” question for prognostication at any time during the 3 year follow-up period

Characteristic	Conservative care		Renal replacement therapy		Difference	95%CI for difference	P value for difference between groups <sup>a</sup>
	n=102 (14%)		n=619 (86%)				
	n	%	n	%			
Advance care directive documented at any time							<0.001
Yes (documented)	21	21%	26	4%	17%	(9%-25%)	
No (including not documented or unknown)	81	79%	593	96%			
“Surprise” question used in prognostication at any time							<0.001
Yes (documented)	9	9%	17	3%	6%	(2%-13%)	

Percentages presented are column percentages

<sup>a</sup>Pearson’s chi-square test for difference between groups

Table 5. Cause of death, place of death and utilization of specialist palliative care services among 247 deceased patients

Characteristic	Conservative care		Renal replacement therapy		P value for difference between groups <sup>a</sup>
	n	%	n	%	
Cause of death					<0.001
Cardiovascular	24	34%	57	33%	
Infectious	1	1%	25	14%	
Cancer	3	4%	11	6%	
Renal failure	21	29%	0	0%	
Withdrawal of RRT	1	1%	45	26%	
Other <sup>b</sup> or unrecorded	22	31%	37	21%	
Place of death					<0.001
Hospital	30	42%	115	66%	
Hospice	10	14%	6	3%	
Nursing home	9	13%	6	3%	
Main residence / Home	9	12%	23	13%	
Unknown	14	19%	25	15%	
Received specialist palliative care					<0.001
Yes (documented)	41	57%	45	26%	
No	16	22%	57	42%	
Unknown	15	21%	73	32%	
<b>Among 86 patients receiving palliative care</b>					
Context of initial palliative care consultation					<0.001
In-patient acute care episode	12	29%	33	73%	
Out-patient referral	29	71%	11	25%	
Unrecorded	0	0%	1	2%	
Palliative care service type					0.03
Joint nephrology / palliative care service	7	18%	7	16%	
Existing regular palliative care service	33	80%	29	64%	
Other <sup>b</sup> / unknown	1	2%	9	20%	
Palliative care personnel involved in delivering care (more than 1 can be selected) <sup>c</sup>					
Palliative care physician	36	88%	27	60%	<0.001
Palliative care nurse - hospital	19	46%	22	49%	0.004
Palliative care nurse - community	17	41%	12	27%	<0.001
GP	7	17%	7	16%	0.07
Other <sup>d</sup>	8	20%	5	11%	0.008
Unknown	6	15%	6	13%	
Duration of palliative care from first consultation to death					0.001
Less than 1 week	6	15%	19	42%	
1 week up to 1 month	11	27%	18	40%	
1 month up to 3 months	10	24%	4	9%	
3 months up to 6 months	8	19%	3	7%	
More than 6 months	6	15%	1	2%	

RRT = renal replacement therapy, GP = General practitioner (primary care physician)

Percentages presented are column percentages

<sup>a</sup> Fisher's exact test or Pearson's chi-square test for difference between groups

<sup>b</sup> Other causes of death include respiratory, services include Nephrology team; Medical / nursing team in regional hospital

<sup>c</sup> Percentages will add to more than 100 as multiple categories can be selected

<sup>d</sup> Other personnel include Renal supportive care clinical nurse consultant; General medical / nursing staff from medical ward in regional hospital; Palliative care social worker